Equalities, Human Rights and Civil Justice Committee

Inquiry into Neurodivergence in Scotland

Notes from online engagement session, 9 February 2026

Breakout group 2

Access to assessments, diagnosis and post-diagnosis support

Participants told Members of their journeys to diagnosis. Several said they were diagnosed later in life and described challenges linked to changing diagnostic criteria over time and inconsistent approaches across regions. One participant said they repeatedly had to undertake assessments that did not reflect their needs.

Some participants noted that many adults discover their neurodivergence through their children's diagnostic journeys.

There was discussion around poor experiences of adult diagnostic pathways, with one stating that they had spent two years on a three-year NHS waiting list when they were informed by letter that said funding for adult assessment, and the whole service, was to be stopped. They described the sudden withdrawal of NHS diagnostic pathways left them, and others, feeling devastated. Another participant discussed how diagnostic pathways can depend on who is allowed to refer into services, describing dismissive responses from GPs.

A number of participants felt they had no choice but to seek private assessments. Participants highlighted that being able to pay for a diagnosis made a significant difference and one described multiple family members needing to fund their own assessments. They felt this created an unjust system where those without financial resources faced long waits or no pathway at all.

Some participants spoke about difficulties around access to medication and shared care arrangements (or lack of) between private and NHS practitioners. Some noted that access to medication depended on having an NHS diagnosis.

A number of participants said they were often not believed or not listened to within healthcare settings. Others noted that autistic presentations of pain differ, which can lead to misunderstanding. Several people shared examples, such as not showing expected outward signs during serious injury or labour. Positive experiences were mentioned too. One participant noted that clear, calm communication at a hospital had made a significant difference to their stress levels.

Participants described the emotional impact of finally having a diagnosis. Several participants described having a diagnosis, including private diagnosis, as validating, liberating, helping them understand their lives and personal history, and improving their wellbeing and mental health. Others noted that without an NHS diagnosis, they were not always taken seriously by schools, GPs and other professionals.

Some participants said post diagnostic support was largely absent unless they happened to find small autistic led organisations themselves. They described how lucky they felt to have found this support. Participants felt that postdiagnostic support should not rely on the third sector alone, as this could lead to sustainability issues and burnout for those running services. One participant said that funding for these organisations was insecure and often diverted to larger organisations instead, which makes support patchy and difficult to access. Some also felt that application processes for funding were inaccessible for autistic people.

Reasonable adjustments, attitudes and discrimination

Participants noted that attitudes of others could affect experiences.

One participant spoke about the negative language used to describe neurodivergent people and said that older derogatory terms are being used again on social media. However, they said that while social media can come under attack, it has also enabled people to talk to each other and find out more about neurodivergence.

Some said autistic people could be more vulnerable to exploitation, including grooming, and felt that this risk was not always understood.

Several participants highlighted that some approaches, such as Applied Behaviour Analysis (ABA) could lead autistic people to mask or doubt their own needs. Others emphasised that small, practical adjustments can matter more than broad policy statements.

Education

In relation to educational settings, one participant felt that without an NHS diagnosis, schools tended to default assuming ‘helicopter parent’ behaviour when only ‘suspected autism’ was noted. They said only a formal diagnosis changed how they were treated. Participants also felt that schools and other services had highly variable levels of understanding.

One participant noted that making simple, relevant adjustments for pupils, even without a formal diagnosis, had a positive effect. They said pupils seemed to value this support. They also shared that being open about their own experience helped some pupils feel more confident and improved their self-esteem.

Employment

Participants noted that autistic communication styles were sometimes misinterpreted as AI-generated in work, education or social contexts. This had led to accusations of plagiarism or assumptions of dishonesty. Some said this created added barriers in job applications, academic work and everyday communication. One participant mentioned that tech screening was stopping autistic people even accessing jobs at the offset.

Criminal justice

One participant described experiences in the criminal justice system around jury duty citations, including processes that created prolonged periods of ‘waiting mode’, which they found difficult and meant that some neurodivergent people disengaged from the process when they could have made a meaningful contribution. In response, others highlighted that small changes in communication or process could make a significant difference to accessibility.

Participants noted that neurodivergent people can face significant challenges in the criminal justice system, whether as victims, offenders, or employees.

Participants raised concerns about the sensory challenges of courts, prisons, police stations and other facilities. Smells and other sensory pressures in prisons can be overwhelming, and when people are trapped in these environments, they may react in the same ways they do when they are overwhelmed in any other setting. They said staff need to understand that people in crisis may react strongly.

Training

One participant said that when they trained as a teacher in the early 1990s, there was no specific information about autism, only general references to challenging children. They recalled that it was not until the late 1990s that anyone mentioned the possibility of teaching autistic pupils. The only training they remembered for many years was an in-service session where a parent spoke about her child’s experiences. They said the next meaningful training they received was not until 2022, and this time it was autistic-led.

Another participant added that they were not convinced things had improved much overall.

Participants widely agreed that training needs to be based on lived experience, led by autistic people, and must be ongoing. One stressed that it cannot be a one-off session and then forgotten, feeling that everyone needs to have a good level of understanding.

Some participants noted their view that much of the current work of training involves undoing the impact of outdated or harmful training.